Aging in the United States: Rethinking Justice, Equality, and Identity Across the Lifespan

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AGING IN THE UNITED STATES: RETHINKING JUSTICE, EQUALITY, AND IDENTITY ACROSS THE LIFESPAN

by Nancy J. Knauer*

INTRODUCTION

On October 22, 2011, the Temple University Beasley School of Law hosted a groundbreaking conference on aging law and policy: Aging in the US: The Next Civil Rights Movement? Over 175 participants attended from across the country, including academics, advocates, policy makers, and practitioners. The goal of the conference was to help focus the national conversation surrounding aging on the broader civil rights implications inherent in elder law and to move the discussion beyond the more traditional concerns of estate planning, benefit eligibility, and health care financing. As many elder law practitioners are well aware, our aging

*I. Herman Stern, Professor of Law and Director of D.C. Programs, Temple University Beasley School of Law. I would like to thank Temple University Beasley School of Law and especially my Dean, JoAnne E. Epps, for supporting the conference and its vision. I would also like to thank the speakers and moderators who gave so generously of their time and ideas. Every person whom I asked to participate in the conference enthusiastically accepted the invitation. This enthusiasm for the project was also widely shared by the staff and administrators at Temple University Beasley School of Law who worked tirelessly to make the event a success. In particular, our Director of Communications, Rebecca Schatschneider, was a tremendous help throughout the planning process, especially with the creation and design of the conference website. Assistant Dean for External Affairs, Deborah Feldman, and Associate Dean for Student Affairs, Marylouise Esten, were both extremely helpful with budgetary considerations, as well as working with alumni groups and the students. Our Director of Special Events, Dorothy Lee, proved once again to be a master of logistics and good cheer. The 2011-2012 Editorial Board and Staff of the Temple Political & Civil Rights Law Review provided excellent support throughout the entire process. Special thanks go to the Editor-in-Chief, Chelsea D. Germak, and the Symposium Editor, Joshua Brand. Josette Finnegan, my legal assistant, flawlessly coordinated all of the travel arrangements. I would also like to thank everyone who attended the event, as well as those of you who contacted me individually to express your regret that you could not attend. I am very encouraged by the level of interest in the topic and the shared commitment to expanding our discussion of aging law and policy to include hard questions involving civil rights and existing age-related disparities. There is much to be done.


2. A significant number of the attendees were also non-lawyers, including social workers, journalists, and health care professionals.

3. Elder law is often categorized as a subset of estate planning and, as such, can be easily dismissed as an area that primarily concerns issues related to financial independence and retirement options. There is no question that these areas are extremely important and can determine the level and quality of care that older people receive. Individuals without financial means have few options regarding
policies and procedures raise profound questions of individual liberty, autonomy, and equality. Guardianship regimes require the state to balance the interests of vulnerable adults with their right to self-determination. The proliferation of age-specific laws designed to protect elders may actually compromise the civil rights of older individuals by denying their autonomy based solely on their age. The regulation of intimacy in long-term care settings infringes on a core liberty interest essential to human dignity.

Professor Nina Kohn has led the call to re-imagine elder law as principally a civil rights project. Her scholarship makes the following important and timely observation: as we age, we all run the risk of outliving our civil rights. Given our rapidly aging society, the suggestion that civil rights diminish with age has broad applicability. It also provides a compelling justification for movement building and organizing. Over the next thirty years, the senior population of the United States will increase dramatically. The number of individuals aged sixty-five and older

care, and those who age without the support of family or friends are at an increased risk of social isolation. See Gardner Harris & Robert Pear, Still No Relief in Sight for Long-Term Needs, N.Y. TIMES, Oct. 24, 2011, http://www.nytimes.com/2011/10/25/health/25seniors.html?_r=1&pagewanted=all ("Unlike the rich, who can afford to pay for services themselves, or the poor, who get help through Medicaid, . . . many members of the middle class have to look after disabled relatives themselves, or pay someone to do it."). However, the emphasis on asset preservation and the highly technical nature of much of the elder law practice can obscure the profound civil rights considerations that are implicit in our aging policy.


6. See Lawrence v. Texas, 539 U.S. 558, 578 (2003) (declaring that the right to liberty under the Due Process Clause includes the right for consenting adults to engage in private sexual conduct without government intervention); see also Evelyn M. Tenenbaum, To Be or to Exist: Standards for Deciding Whether Dementia Patients in Nursing Homes Should Engage in Intimacy, Sex, and Adultery, 42 IND. L. REV. 675, 709 (2009) (explaining that nursing home administrators and staff’s decision whether to allow a married resident to continue an adulterous relationship “limits [the resident’s] liberty and deprives him of respect and dignity”).


8. Professor Kohn writes: The past two decades have witnessed a surge of interest in protecting senior citizens from victimization. As social service providers and policymakers have become increasingly aware of and sensitized to the problems of elder abuse and neglect—problems estimated to affect three to five percent of seniors annually in the United States—they have responded by advocating for new laws to protect senior citizens from mistreatment. States have, in turn, enacted a variety of new statutes aimed at protecting older adults. Although well-intentioned, many of these statutes take a paternalistic approach that has serious—and potentially unjustifiable—civil rights implications for the seniors they are designed to protect. . . . The effect is that, in some states, a person’s constitutional rights will be curtailed simply because he or she attains the age of sixty or sixty-five.

Id. at 1054-55.

will more than double, and the number of individuals aged eighty-five and older will more than triple.\textsuperscript{10} By 2030, one out of every five Americans will be sixty-five or older.\textsuperscript{11}

Professor Kohn was the keynote speaker at the conference, and her opening address made a persuasive case that it was time for a civil rights movement that would champion the interests of older individuals. Moreover, she argued that an elder rights movement has the potential to revolutionize the way we think about the aging process and its relationship to fundamental issues of justice, equality, and identity.\textsuperscript{12} Although Professor Kohn’s address specifically mentioned the role lawyers should play in building such a movement, the true reach of her appeal is universal. The notion of elder rights encompasses concerns that eventually will affect each and every one of us. Regardless of our race, ethnicity, gender identity, class, or sexual orientation, we all hope that one day we will be afforded the opportunity to age safely and without fear. In this way, aging represents the ultimate “Big Tent” issue and provides a rare opportunity to build a thoughtful and inclusive movement that incorporates the lessons learned from other social movements, as well as the insights of critical theory.\textsuperscript{13}

Of course, there is no easy roadmap to follow and no easy solution. The call for an elder rights movement will carry with it numerous obstacles to movement building, in addition to the weight of a much broader critique of rights-based arguments.\textsuperscript{14} Even the designation “elder” or “elder law” may be seen as further reinforcing the marginalization of older individuals, leading to a concern that an elder rights movement may simply reinscribe ageism and age-related bias.\textsuperscript{15} When addressing these issues, advocates and policymakers will need to think creatively

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\textsuperscript{10} By 2050, the U.S. population aged sixty-five and older is projected to be 88.5 million, which is more than twice the estimated 2010 population of 40.2 million. \textit{Id.} at 1. The number of individuals aged eighty-five and older, referred to as the “oldest old,” is projected to increase from 5.8 million in 2010 to 19 million in 2050. \textit{Id.} at 3.
\textsuperscript{11} \textit{Id.} at 1.
\textsuperscript{13} In terms of its general applicability, an aging population will also increase the “dependency ratio” significantly. \textit{Aging Boomers Will Increase Dependency Ratio, Census Bureau Projects, U.S. CENSUS BUREAU} (May 20, 2010), http://www.census.gov/newsroom/releases/archives/aging_population/cb10-72.html. The dependency ratio reflects the number of individuals aged sixty-five and older compared with every one hundred individuals of traditional working age. \textit{Id.} The increase in the ratio has the potential to impact a broad range of social and economic policy decisions and institutions.
\textsuperscript{14} Professor Kohn acknowledges these challenges in her work. \textit{See, e.g., Kohn, supra note 7, at 105 (“[R]ights-talk” has come under attack from both right and left wing intellectuals.”). Professor Kohn concludes that “[t]he language of rights is compelling to the American public even if it is not in vogue among legal scholars, just as appeals to constitutional rights can be compelling to the public even when they would not sway the courts.” \textit{Id.}
\textsuperscript{15} Sue Westwood, “I May Be Older, but I Ain’t No ‘Elder’”: A Critique of “Elder Law,” 21 TEMP. POL. & CIV. RTS. L. REV. XX, XX+1 (2012). Westwood argues that “the concepts of ‘Elder’ and ‘Elderly Client’ specialist legal practice, rather than empowering and enhancing the legal rights of older people, instead reinforce the stereotyping of people based on chronological age in general, and older people in particular, both in law and wider society.” \textit{Id.}
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and pursue multiple sites of intervention at the federal, state, and local levels. As they craft policy solutions, strategic institutional choice can help them evaluate the quantum and quality of the relief available from the various institutional players. Adopting a multifaceted approach, elder rights can be simultaneously advanced through legislation, administrative rulemaking, and the courts. The market can also play a valuable role in changing the perception of the aging process, as the vast Baby Boomer generation transitions toward retirement age. Throughout this enterprise, the personal stories of older individuals, their families, and their caregivers will provide the all-important moral imperative that will serve to animate the claims for relief and forge connections across diverse communities and across the generations.

At the conference, twenty-one leading scholars and advocates engaged these cutting edge public policy issues, including topics related to health care, guardianships, caregiving, institutionalized elders, and the special needs of minority populations. Throughout the day, the panelists presented novel proposals and observations that began to set the framework for an elder rights movement that would highlight questions of justice, equality, and identity. A number of the panelists also shared personal stories about caregiving and navigating end-of-life decision making that provided an important context to the more theoretical discussions. Indeed, the seamless integration of personal narrative illustrates the


18. This approach will avoid the mistake of “single institutionalism.” KOMESAR, supra note 17, at 24-26. Komesar explains that “single institutionalism” is based on the “implicit assumption . . . that a perfect or idealized institution is waiting in the wings.” Id. at 24. He concludes that whereas single institutionalism is “mistaken in conception” it is “useless in execution.” Id. at 26.


20. The conference was organized into five panels relating to the following subjects: health care, guardianship, supportive services, institutional settings, and intersectionality. Aging in the U.S.: The Next Civil Rights Movement?, supra note 1.

21. Id.

22. See, e.g., Debra H. Kroll, To Care or Not to Care: The Ultimate Decision for Adult Caregivers in a Rapidly Aging Society, 21 TEMP. POL. & CIV. RTS. L. REV. XX, XX+2 (2012) (discussing her experiences as a caregiver for her “ninety plus mother”).
close connection that exists between theory and practice. As I have said in other venues, theory and practice are but two sides of the same coin. Practice necessarily informs theory, and theory necessarily elucidates practice. The power of the collected personal narratives reminds us that individual stories and concerns are what drives our theory and what gives our practice meaning.

The Temple Political & Civil Rights Law Review is proud to publish a number of the papers that were presented at the conference in this special issue. At least one paper from each of the five panels is included, as well as Professor Kohn’s inspiring keynote address. Taken together, these articles represent an important first step in the process of constructing an inclusive and welcoming elder rights agenda. In terms of scholarship, the challenge going forward will be to continue to articulate the disparities and differences among elders while simultaneously advancing a common cause. To do this, we will need to develop a robust civil rights-based theory of aging that incorporates and respects difference. Such a theory will not only help inform policy proposals but also enrich our larger understanding of identity. Although intersectionality has taught us that identity, as it is lived and experienced, is a multivalent process, a theory of aging will illustrate that identity formation is also historically contingent. In other words, age and the aging process add a new dimension to identity—not merely another point of intersection.

The following discussion provides an overview of the various presentations and panels. Additional information regarding the conference and the participants is available at the conference website at http://www.law.temple.edu/aging.

23. Theory and practice are often presented as an either/or, but they represent a false dichotomy. As with any binary construction, each concept is mutually dependent on the other. The legal academy has been embroiled in a debate over the theory/practice divide for some time. See generally William M. Sullivan et al., Carnegie Found. for the Advancement of Teaching, Educating Lawyers: Preparation for the Profession of Law (2007).


25. Id.

26. Id.

27. See Aging in the U.S.: The Next Civil Rights Movement?, supra note 1 (describing the five panels).


29. For a discussion of a “scholarship of articulation,” see Nancy J. Knauser, Heteronormativity and Federal Tax Policy, 101 W. Va. L. Rev. 129, 226-32 (1998). Another challenge may also be to arrive at a suitable description of the project that does not rely on arguably pejorative terms such as “elder” or “senior.” See Westwood, supra note 15, at XX+21.


I. KEYNOTE ADDRESS AND POLICY UPDATE

The day started with Professor Kohn’s keynote address, which is included in this issue.32 Leaving no question as to where she stood on the central question of the conference, Professor Kohn elected to omit the question mark from the title of her talk: Elder Rights: The Next Civil Rights Movement.33 In her address, Professor Kohn made a persuasive argument that elder rights should form the basis of the next civil rights movement and further argued that framing elder law issues in terms of civil rights is “imperative from a law reform perspective.”34 Building on her earlier articles, such as Outliving Civil Rights35 and The Lawyer’s Role in Fostering an Elder Rights Movement,36 Professor Kohn summarized “a wide range of civil rights concerns that undermine not only the[] physical and psychological well-being [of older Americans] but also their personal freedom and, ultimately, their human dignity.”37 She also outlined the “critical role” that the legal community can play in the creation of an elder rights movement and discussed the construction of social movements more generally.38 Ultimately, Professor Kohn’s address calls for a paradigm shift, challenging us to begin the discussion about “the intersection of aging and civil rights” and take steps to safeguard our civil rights and liberties across the lifespan.39

Immediately following Professor Kohn’s keynote address, M.T. Connolly, a 2011 MacArthur Fellow and the Director of Life Long Justice, presented a federal policy update that she subtitled How Change Happens.40 We have included an expanded version of her talk, along with some of the questions it generated, in this issue. Ms. Connolly was the chief architect of the Elder Justice Act (“EJA”) while she was at the Department of Justice, and she detailed the process by which the proposed legislation became law.41 The EJA was enacted in 2010 as part of the Patient Protection and Affordable Care Act42 and represents the first coordinated effort on the federal level to prevent and combat elder abuse.43

32. Kohn, supra note 12.
33. Id.
34. Id. at XX+8.
35. Kohn, supra note 7; see also Kohn, supra note 5.
37. Kohn, supra note 12, at XX.
38. Id. at XX+4+5.
39. Id. at XX+8.
II. HEALTH CARE, SELF-DETERMINATION, AND AUTONOMY

The first full panel discussion of the day addressed issues related to Health Care, Self-Determination, and Autonomy. Moderated by Naomi Karp, the panel included two speakers: Michele Mathes and Lois Shepherd. At the time, Ms. Karp was the Senior Strategic Policy Advisor for the Consumer and State Affairs Team of the AARP Public Policy Institute. While at the AARP Public Policy Institute, Ms. Karp did extensive research on physician orders for life-sustaining treatment (“POLST”) programs. She is currently a Policy Advisor at the Consumer Financial Protection Bureau, Office of Older Americans.

Lois Shepherd, Professor of Law at the University of Virginia School of Law and Director of Programs in Medicine and Law at the Center for Biomedical Ethics and Humanities, spoke on end-of-life ethics. An expert on end-of-life decision making and bioethics, Professor Shepherd entitled her presentation The End of End of Life Law and Ethics. She argued in favor of an “end to end-of-life law,” saying that we should abolish many of the special rules that have been created over the last thirty-five years for making medical decisions in situations in which death may occur. Professor Shepherd asserted that such rules rely on idealized and unrealistic notions of patient autonomy and are driven largely by political ideology rather than concern for patients. She proposed that questions about medical care at the end of life should be approached like other important decisions about medical care—with consideration to patient’s wishes, values, interests, and relationships—and without special laws.

At the time of the conference, Michele Mathes was the Director of Education and Research at the Center for Advocacy for the Rights and Interests of the Elderly. A noted bioethicist, Ms. Mathes is currently a Senior Associate at the Center for Ethics and Professionalism at the American College of Physicians. Ms. Mathes presented her paper, Health Care and the Aged: Arguing Equality in the Absence of a Right, which is also included in this issue. Her paper makes the important observation that it is difficult to frame an argument in favor of equal access to health care for elders when health care itself is not a recognized civil right. Acknowledging that “the basis for older adults’ equal right to health care does not lie in the law . . . exclusively,” Ms. Mathes builds a strong moral argument to

44. Unfortunately, Barbara A. Soniat, Associate Professor of Social Work at Catholic University and the Director of the Center for Global Aging was unable to attend the conference. She had been scheduled to present her research on Autonomy and Vulnerable Adults. See, e.g., Barbara A. Soniat, Dementia Patients Who Live Alone: Research and Clinical Challenges, 52 J. AM. GERIATRICS SOC’Y 1 (2004).


support the right to equal access. She concludes that the authority for such a right ultimately lies "in the recognition of aging as our shared fate and vulnerability and in the moral imperative of equality of respect for our fellow human beings in all their diversity of race, religion, gender, ethnicity, and, yes, age." 

III. GUARDIANSHIP, VULNERABILITY, AND AUTONOMY

The second panel was organized around issues relating to Guardianship, Vulnerability, and Autonomy. Moderated by Professor Theresa Glennon, a family law scholar from Temple University Beasley School of Law, the panel included three speakers: Larry Frolik, Carolyn Dessin, and Elizabeth Loewy. The panelists considered topics related to guardianship reform, the challenges presented by vulnerable consumers, and the legal response to economic exploitation and abuse. Larry Frolik, the Distinguished Faculty Scholar and Professor of Law from the University of Pittsburgh School of Law, is an internationally recognized expert on guardianship law. In his talk, "Guardianship: Vulnerability & Protection versus Autonomy & Independence," Professor Frolik laid the groundwork for the panel by identifying the competing interests that are represented in guardianship regimes, as well as the values reflected by the various decision making standards and reform measures.

Carolyn Dessin, Professor of Law at the University of Akron School of Law, addressed the impact of pre-dispute binding arbitration agreements on vulnerable consumers, specifically elders. Her paper, "Arbitrability and Vulnerability," is included in this issue. While recognizing the benefits of arbitration, Professor Dessin notes the increase in the number of challenges being brought against pre-dispute binding arbitration agreements that involve vulnerable consumers. With respect to vulnerable elders, she notes that these challenges most often arise in the context of nursing home agreements, contracts signed by attorneys in fact, and trust disputes. Professor Dessin ultimately calls for Congress to review the scope of the Federal Arbitration Act in light on the broad interpretation of the Act by the U.S.

48. Id. at XX+10.
49. Id.
50. Unfortunately, Alison E. Hirschel, a Public Interest/Public Service Faculty Fellow at the University of Michigan Law School and an Elder Law Attorney with the Michigan Poverty Law Program, was unable to join us. Ms. Hirschel had been scheduled to moderate the panel on Guardianship, Vulnerability, and Autonomy.
51. Professor Frolik is the author of numerous treatises and articles that helped to define the field of elder law. See, e.g., LAWRENCE A. FROLIK & ALISON BARNES, ELDERLAW: CASES AND MATERIALS (3d ed. 2003).
55. Id. at XX+12-XX+13.
56. Id. at XX+6-XX+12.
Supreme Court. 57

Elizabeth Loewy is the Attorney-in-Charge of the Elder Abuse Unit with the Special Prosecutions Bureau/Special Victims Bureau of the New York County District Attorney’s Office. Ms. Loewy’s presentation on *Elder Economic Exploitation* highlighted the difficulties faced in prosecuting crimes against the elderly. Her compelling PowerPoint presentation included crime scene photos showing instances of elder abuse and neglect, as well as evidence of financial exploitation. Ms. Loewy was the lead prosecutor in the case against Brooke Astor’s son, Anthony D. Marshall, which captivated the media and drove home the message that neglect and abuse can occur regardless of socio-economic class or notoriety. 58 The case originally attracted the attention of prosecutors when Mrs. Astor’s grandson raised questions regarding the way his father was handling Mrs. Astor’s finances, including the choices he was making with respect to her personal care. 59 After a lengthy criminal trial, Mr. Marshall was found guilty on numerous counts involving financial exploitation but remains at liberty pending appeal. 60 Mrs. Astor’s lawyer, Francis X. Morrissey, was also convicted of fraud and forging a codicil. 61

IV. ELDERS, FAMILY, AND THE STATE

The first panel of the afternoon was organized around the intersection of *Elders, Family, and the State*. The speakers on this panel took a more local and individualized approach to the issues related to aging law and policy. Moderated by Kathy Mandelbaum, Associate Professor of Law and Director of the Graduate Tax Program at Temple University Beasley School of Law, the panel included three speakers: Kim Dayton, Alicia Kelly, and Debra Kroll. Focusing on the daily challenges of aging, the panelists examined three different sources of support and supportive services: municipal governments, spouses and partners, and informal caregivers. Professor Mandelbaum began the panel with moving remarks, detailing the painful choices that a family can face when they assume the responsibility for caring for a family member living with dementia. 62 Throughout the day, a number of speakers and audience members referenced the looming epidemic of dementia

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57. Id. at XX+15.
61. Id.
and the considerable challenges that it will present in terms of caregivers and the limited options for long-term care. The World Health Organization estimates that there are approximately 35.6 million people worldwide who are living with dementia and that this figure will nearly double every twenty years. Kim Dayton, Professor of Law and Director of the Center for Elder Justice and Policy at William Mitchell College of Law, is an internationally recognized expert on elder law. She presented the results of an exciting new research project that she had undertaken with another international elder law scholar, Israel Doron. Funded by a grant from the Borchard Foundation, the research examines the ability of municipal law and regulations to address the needs and concerns of older individuals. Their findings and conclusions are set forth in their co-authored article included in this issue titled: “Thinking Locally: Law, Aging, and Municipal Government: Findings from a National Survey.” Professors Dayton and Doron selected a sample of 152 U.S. cities and towns to determine whether they had “utilized their state-delegated authority to its fullest extent in an effort to further the rights of their older residents.” The data confirmed the original hypothesis that cities and towns were not doing all that they can to address the needs of their older residents. Professors Dayton and Doron conclude that this under-utilization presents a great opportunity for advocates and policy makers to harness municipal power to serve older Americans: “there is enormous room for action, initiatives, and creative, original approaches to addressing the often unique economic, social, and cultural issues facing the elderly.”

Alicia Kelly, Associate Professor of Law at Widener Law School, has written widely about the economic behavior within the family, specifically on patterns of income sharing between spouses. For the conference, Professor Kelly turned her

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63. For 2012, the estimated cost of caring for individuals with Alzheimer’s disease and other forms of dementia in the United States was $200 billion. Robert Preidt, Alzheimer’s, Dementia Care to Cost $200 Billion This Year, PHILLY.COM (Mar. 8, 2012), http://www.philly.com/philly/health/HealthDay662557_20120308_Alzheimer_s_Dementia_Care_to_C ost_U_S__200_Billion_This_Year.html; see Stephanie Saul, Taking on Alzheimer’s, N.Y. TIMES, June 10, 2007, http://www.nytimes.com/2007/06/10/business/yourmoney/10alz.html (describing a “booming Alzheimer’s” epidemic”).

64. Dementia: Fact Sheet No. 362, WORLD HEALTH ORG., http://www.who.int/mediacentre/factsheets/fs362/en/ (last updated Apr. 2012). The World Health Organization reports that, worldwide, 35.6 million people have dementia, and every year there are approximately 7.7 million new cases. Id. The number of people with dementia is expected to rise to 65.7 million in 2030 and 115.4 million in 2050. Id.


68. Doron & Dayton, supra note 16.

69. Id. at XX+6.

70. Id. at XX+16.

71. See, e.g., Alicia B. Kelly, Money Matters in Marriage: Unmasking Interdependence in Ongoing Spousal Economic Relations, 47 LOUISVILLE L. REV. 113 (2008) (exploring the interaction of money,
focus to older couples and examined the economics of caregiving that arise within a family. Her paper titled *The Economics of Caring and Sharing in Elder Couples* is included in this issue. As couples age together, they often assume reciprocal and overlapping caregiving responsibilities. The high cost of long-term care and the challenges associated with aging in place can create multiple stresses on family finances. Illness and disability can also disrupt familiar roles within the family. When looking at economic behavior between older spouses, however, it is also important to remember that aging is disproportionately a gendered endeavor.

A longer life expectancy for women and an earlier age at first marriage combine to make it more likely that a wife will outlive her husband. Accordingly, older men are more likely to be aging with the assistance of a spouse, whereas women often face years of widowhood at the end of life. Professor Kelly’s article makes an important addition to the economic study of the family and underscores that much work remains to be done in order to understand the unique economic stresses experienced by older couples.

Debra Kroll, Associate Clinical Professor of Law and Director of the Elderly Law Project at Temple University Beasley School of Law, continued the discussion of caregiving but shifted our focus to the pressures placed on informal caregivers, specifically adult children. Her article, *To Care or Not to Care: the Ultimate Decision for Adult Caregivers in a Rapidly Aging Society*, is included in this issue. Writing from the perspective of an adult child who is caring for her “ninety plus mother,” Professor Kroll provides a compelling and personal account of what she refers to as the decision “to care or not to care.” Currently, eighty percent of all elder care is performed by informal caregivers who are most often a child or younger relative. As our society rapidly ages, Professor Kroll warns of the increasing responsibility that will be placed on the shoulders of informal caregivers. Professor Kroll intends her article to serve as “a roadmap, both for other practicing lawyers and for their clients, of the legal needs inherent in this aging process.” She concludes that aging “is a process we will all experience, either as a caregiver or a care receiver . . . . It is imperative, given the numbers of elderly we are projecting, that the cultural view of aging is altered and that all ages

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73. Women are disproportionately represented in the ranks of older Americans. In 2010, fifty-seven percent of those aged sixty-five and older were female. U.S. Census Bureau, *supra* note 13. Women represented sixty-seven percent of the individuals aged eighty-five and over. *Id.*

74. WILLIAM KORNBLUM, SOCIOLOGY IN A CHANGING WORLD 351-52 (9th ed. 2011).


78. *Id.* at XX, XX+2.


81. *Id.* at XX+2.
are integrated into the fabric of community life.”

V. ELDERS AND LONG-TERM CARE

The next panel was dedicated to concerns related to *Elders and Long-Term Care*. Moderated by Ms. Connolly, the panel featured three speakers: Eric Carlson, Daniel Redman, and Evelyn M. Tenenbaum. Eric Carlson is the Directing Attorney at the National Senior Citizens Law Center (“NSCLC”). He presented an important overview of recent trends in the regulation of long-term care options. Mr. Carlson was followed by Daniel Redman, who is the Elder Law Project Fellow at the National Center for Lesbian Rights (“NCLR”). Both the NSCLC and the NCLR were co-authors of a pioneering study, *LGBT Older Adults in Long-Term Care Facilities: Stories from the Field*. Mr. Redman’s paper, *They Stood Up for Us: Advocating for LGBT Elders in Long-Term Care*, is included in this issue.

Providing a rich historical background, Mr. Redman details the many ways in which LGBT elders differ from their non-LGBT peers and explains how these differences make them more vulnerable to discrimination and harassment in long-term care settings. He also offers heart-breaking examples of same-sex couples and transgender elders who were refused care or subjected to bullying and harassment on account of their sexual orientation or gender identity. Mr. Redman concludes his article with a blueprint for change and outlines a series of practical “steps for each of us to take to fight the injustices LGBT elders face.”

Evelyn M. Tenenbaum is a Lawyering Professor at Albany Law School and a Professor of Medical Education at Albany Medical College. Professor Tenenbaum has previously written on topics related to informed consent and authored a groundbreaking article regarding a dementia patient’s right to intimacy in long-term care settings.

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82. *Id.* at XX+2+3.


87. *Id.* at XX+9-XX+10.

88. See *id.* at XX+11 (relaying the experiences of a gay nursing home resident whose assigned aid refused to bathe him, a gay resident who committed suicide after staff relocated him to the dementia ward instead of addressing other residents’ bullying, and a transgender resident who was prevented from eating and socializing with other residents).

89. *Id.* at XX+14-XX+15.
term care settings, To Be or to Exist: Standards for Deciding Whether Dementia Patients in Nursing Homes Should Engage in Intimacy, Sex, and Adultery.\textsuperscript{90} Professor Tenenbaum expanded on that work with her presentation and in her article that is included in this issue, Sexual Expression and Intimacy Between Demented Nursing Home Residents: Balancing the Current Interests and Prior Values of Heterosexual and LGBT Residents.\textsuperscript{91} Recognizing that the topic of intimacy involves “[s]ome of the most sensitive and controversial issues in nursing homes today,” \textsuperscript{92} Professor Tenenbaum proposes a balancing test to be used when the expression of intimacy conflicts with an individual’s “former critical interests.”\textsuperscript{93} She concludes: “[t]he most informed and humane decisions regarding sexual relations between members of both the heterosexual and LGBT communities will be reached by respecting the whole person—who they were and most especially who they are now.”\textsuperscript{94}

VI. INTERSECTIONALITY

The final panel of the day was dedicated to the topic of Intersectionality and a discussion of the complexity of identity constructions. The panel was moderated by Sue Westwood from Keele University, United Kingdom, and had three speakers: Peggie R. Smith, Hilary Meyer, and myself. Ms. Westwood began the panel with introductory remarks regarding intersectionality and made an important contribution to this special issue with her paper “I May be Older, but I Ain’t No ‘Elder’”: A Critique of “Elder Law.”\textsuperscript{95} Ms. Westwood takes issue with the emergence of “elder law” as a growing area of legal specialization, suggesting that the emphasis on elders as a distinct interest group may “inadvertently reinforce[] the negative stereotyping and marginalisation [sic] of older people.”\textsuperscript{96} After providing a persuasive critique of the use of the category of “elder” in civil rights discourse, Ms. Westwood offers several alternative ways to serve the interests of older clients, such as “taking an anti-ageist stance” and contributing to a civil rights movement that addresses “not just issues affecting older people but the wider issues of age categorisation [sic] in law and society and disability rights, affecting both older and younger people.”\textsuperscript{97} She concludes that “[l]awyers are uniquely positioned to have a key part of changing [age stereotyping], enabling people of all ages to be self-determining, based on their capacity to do so, not their chronological stage or

\begin{itemize}
  \item \textsuperscript{90} Tenenbaum, supra note 6.
  \item \textsuperscript{92} Id.
  \item \textsuperscript{93} Id. at XX+5; see also Denise Grady, When Illness Makes a Spouse a Stranger, N.Y. Times, May 5, 2012, http://www.nytimes.com/2012/05/06/health/a-rare-form-of-dementia-tests-a-vow-of-for-better-for-worse.html?pagewanted=all (discussing the ravages of frontotemporal dementia).
  \item \textsuperscript{94} Tenenbaum, supra note 91, at XX+24.
  \item \textsuperscript{96} Id. at XX+25.
  \item \textsuperscript{97} Id. at XX+20, XX+25.
\end{itemize}
Peggie R. Smith, the Charles Nagel Professor of Law at Washington University in St Louis, is a leading scholar on the regulation of care work.\(^9\) Her presentation shifted our focus to the industry of paid home health care and the estimated 958,000 workers who perform essential and highly intimate services for approximately twelve million individuals annually.\(^10\) In her presentation *Intimacy, Race & Personal Preferences in Home Care*, Professor Smith highlighted the continuing importance of race and how it impacts the hiring decisions. The presentation was an important reminder that the elder care industry includes many low-skilled and low-paid workers who are often denied basic workplace protections.

Hilary Meyer is the Director of the National Resource Center on LGBT Aging. With funding from the U.S. Department of Health and Human Services, the National Resource Center functions as a clearinghouse for information and resources on topics related to LGBT aging.\(^11\) Ms. Meyer’s article, *Federal Policy, Activism, and LGBT Older Adults*, is included in this issue.\(^12\) In her article, Ms. Meyer makes the point that the elder rights movement must pay particular attention to “marginalized groups, such as LGBT older adults, as they are often the most vulnerable.”\(^13\) She outlines a number of policy solutions that will address the special needs of older individuals with intersecting and marginalized identities. These solutions include policy reform that will address health care disparities and insure culturally competent care, as well as grassroots advocacy related to coalition building on the local level.\(^14\)

As the conference organizer, I reserved the last spot of the day for myself. My goal had been to make some general remarks about the ability of critical legal theory to inform aging law and policy. In my talk titled *Critical Theory and Elder Law*, I wanted to underscore that the very premise of this conference—the notion that one can outlive his or her civil rights—presupposes that each of us is fully possessed of our civil rights in the first instance. Sadly, this is just not the case. In the United States, numerous segments of the population continue to encounter systemic bias and remain marginalized—some groups, such as LGBT individuals, still lack formal equality.\(^15\) For these individuals, the aging process can accentuate

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98. Id. at XX+25.


103. Id. at XX+9.

104. Id. at XX+5-XX+6, XX+7.

105. In terms of formal equality, same-sex couples are only permitted to marry in a handful of states. *Marriage Equality & Other Relationship Recognition Laws*, HUM. RTS. CAMPAIGN, http://www.hrc.org/files/assets/resources/Relationship_Recognition_Laws_Map%281%29.pdf (last
pre-existing vulnerabilities and amplify points of difference. Bias that an individual could have weathered in middle age may appear much more threatening to someone whose capabilities and resources have been reduced with age.\textsuperscript{106} Seemingly neutral mainstream aging policies can both reflect and reinforce existing disparities.

Inspired by the other speakers who drew on their personal experiences, I also decided to say a few words about my grandmother who had died six days earlier at the age of ninety-six.\textsuperscript{107} Once the highest-ranking woman in the federal government, she had been a consumer advocate who worked tirelessly to protect vulnerable consumers, especially seniors.\textsuperscript{108} As her dementia progressed, however, it was she who needed the protection. Armed with a durable power of attorney, advance directive, and a do-not-resuscitate order, she aged in place, but it took a village to make it happen. She spent sixteen months in hospice care, preferring to do things on her own time, as we advocated and argued on her behalf.\textsuperscript{109} Her death from advanced non-Alzheimer’s dementia was frankly unspeakable. At the end of a very long day, all we could say to the papers was that she had “passed away peacefully at her home in Washington, DC surrounded by her family.”

**CONCLUSION**

The demographic shifts that are projected to occur over the next several...

\textsuperscript{79} See STAFF OF S. SPECIAL COMM. ON AGING, 98TH CONG., CONSUMER FRAUDS AND ELDERLY PERSONS: A GROWING PROBLEM (Comm. Print 1983), available at http://aging.senate.gov/reports rpt183.pdf (last visited May 13, 2012). The Report’s Letter of Transmittal specially acknowledges “the assistance of Virginia Knauer, Special Assistant to the President, and Director of the U.S. Office of Consumer Affairs.” Id. at III.

decades have the potential to alter our basic societal institutions in many fundamental and unforeseen ways. As the focal point of caregiving, the family will continue to shoulder the bulk of unpaid care responsibilities, making the situation all the more dire for individuals who age without the support of family or friends. The increasing demand for care, however, will place a strain on our already inadequate health care system, as families are unable to take on the added responsibility. Moreover, the growing numbers of the “oldest old” and rising incidence of dementia will pose serious questions regarding the level and quality of care provided, not to mention the cost. The law’s protective impulse to safeguard vulnerable individuals must be exercised in a way that preserves our inherent dignity and right to self-determination. When we consider individuals living with dementia or other cognitive impairments, however, this may mean coming to terms with the difference between their historic self and their present self.

These demographic shifts also present difficult questions of inter-generational equity and resource allocation. As the dependency ratio increases, fewer workers will be supporting an ever-increasing older population. We will face conflicting priorities with respect to tax revenues, entitlements, and health care spending. A movement to advance the civil rights interests of older individuals can provide valuable input and perspective, and the members of the legal profession and the academy have an important role to play in building such a movement. We have a unique opportunity to change the conversation surrounding aging and begin to rethink issues of justice, equality, and identity across the lifespan. It is important to remember that, despite our best efforts, time waits for no one.

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110. See, e.g., Soniat supra note 44 (discussing the many challenges facing the unbefriended elder or elders who live alone).
111. See supra notes 10, 63-64 (providing statistics on the growing elderly population, the rising cost of care, and the increased rate of dementia).
112. See, e.g., Tenenbaum, supra note 91, at XX+3 (describing the person living with dementia as the “now” person, who has experiential interests which may conflict with what the individual had expected when he was competent).
113. See supra note 13 (explaining the “dependency ratio”).
114. In the fifteenth century morality play, Everyman, the character Death (Dethe) says:
   The ayaylith not to crye, wepe, and praye:
   But hast the lyghtly that thou were gone this journye:
   And preve thy frendes yf thou can;
   For, wete thou well, the tyle abydeth no man.
ANONYMOUS, EVERYMAN: BEING A MORALLE PLAYE OF THE XV CENTURIE 13 (Montrose Jonas Moses et al. eds., 1903) (emphasis added).